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# Understanding integrated care pathways in palliative care using realist evaluation: a mixed methods study protocol

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## ABSTRACT

**Introduction:** Policy- and evidence-based guidelines have highlighted the need for improved palliative and end-of-life care. However, there is still evidence of individuals dying undignified deaths with little pain control, therefore inflicting unnecessary suffering. New commissioning powers have enabled a 2-year pilot of an innovative integrated care pathway (ICP) designed to improve arrangements for individuals with life-limiting illnesses requiring palliative care. A novel feature of the ICP is its focus on palliative care over the last 6 months of life, aiming to intervene early to prepare for and ensure a good death. What is not known is if this pathway works, how it works and who it works for.

**Methods and analysis:** A realist evaluation and a complex analytical framework will investigate and discover context, mechanism and outcome conjectures and configurations of the ICP and thus facilitate exploration of how it works and who it works for. A mixed methods approach will be used with small sample sizes to capture the breadth of the ICP. Phase 1 will identify if the pathway works through analysis of NHS Morbidity Information Query and Export Syntax data, locality Death Audit data and the Quality of Dying and Death Questionnaire. Phase 2 employs soft systems methodology with data from focus groups with health professionals to identify how the pathway works. Phase 3 uses the Miller Behavioural Style Scale and interviews with palliative care patients and bereaved relatives to analyse communication in palliative care.

**Ethics and dissemination:** Ethical approval has been granted from the NHS local ethics committee (REC reference number: 11/NE/0318). Research & Development approval has been gained from four different trusts, and relevant voluntary organisations and the local council have been informed about the research. This protocol illustrates the complexity inherent in evaluating a palliative care ICP. Identification of whether the pathway works, how it works and who it works for will be beneficial to all practices and other care providers involved as it will give objective data on the impact of the ICP. Results will be disseminated throughout the study for continuous quality improvement of the ICP. Outcomes from each data collection phase will be disseminated separately if analysis warrants it; all data collection will be utilised in the realist evaluation. The research provides a potential for the dissemination of the

## ARTICLE SUMMARY

### Article focus

■ This article is a protocol of a realist evaluation of a palliative care ICP, which was developed in Primary Care by health practitioners. The ICP itself uses elements of long-term chronic illness care in order to provide holistic, supportive, high-quality palliative care. The focus of the article is to detail how the ICP will be evaluated, using a variety of data collection tools, which will identify contexts and mechanisms that lead to improved outcomes, thus taking the main focus away from just the outcomes alone. The identification of contexts and mechanisms for improved outcomes is known as realist evaluation and will provide a better knowledge of the essential conditions of effectiveness when the ICP is implemented in other localities.

### Key messages

■ The key aim of this article is to detail the creation of a complex realist evaluation, which utilises a unique and varied methodological framework. It is hoped that through this article, others will understand the groundwork needed to set up and execute a realist evaluation.

### Strengths and limitations of this study

- The protocol details a complex evaluation of a unique palliative care ICP using a new and innovative methodology: realist evaluation.
- Some may perceive the small sample sizes in the qualitative sections of the study as a weakness. However, the aim of the study is not to find a robust causal mechanism; this would be premature with an ICP in its infancy. The aim is to unpack the contexts and mechanisms that work in certain circumstances, from this conditions crucial for effectiveness can be highlighted, which are essential for implementation of the ICP in other localities.
- The ICP involves 15 general practitioner practices, which collectively care for 80 300 patients. The study described will use Morbidity Information Query and Export Syntax and Death Audit data from all 15 practices and will conduct the other sections of research within selected practices, both rural and suburban.
- Finally, palliative care is commonly misunderstood in the literature and in the field. This paper addresses this confusion and fills a gap in the literature.

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pathway to other localities through the transferable knowledge it will generate, from its focus on the contexts that are crucial for successful implementation, the mechanisms that facilitate implementation and the outcomes achieved.

### BACKGROUND

End-of-life and palliative care are local, regional and national priorities requiring continuous evaluation and improvement. Policy and evidence-based guidelines have identified a need for improved palliative and end-of-life care services.<sup>1 2</sup> However, there is still evidence in the field, media and literature of individuals dying undignified deaths with little pain control, therefore inflicting unnecessary suffering on the patient and on their relatives.<sup>3 4</sup>

In one semirural locality in the North East of England, an innovative integrated care pathway (ICP) has been created through use of new commissioning powers to implement and continually improve arrangements for individuals with life-limiting illnesses requiring palliative care. The ICP, which has been in use since January 2010, includes several interventions: palliative care registration, Advance Care planning, a traffic light system of illness progression, the ordering of just in case drugs and use of the voluntary sector to fill gaps in care. The ICP involves 15 general practitioner (GP) practices, which collectively care for 80 300 patients. The project reported here has been jointly funded by the NHS North of Tyne in collaboration with Northumbria University and will provide an opportunity to explore in detail the ways in which the pathway works.

In the research literature, improvements in end-of-life care through the use of ICPs have been noted.<sup>5 6</sup> The most researched and reported ICP related to end-of-life care is the Liverpool Care Pathway (LCP)<sup>7</sup>; however, this ICP focuses solely on the last few days of life as opposed to palliative care for those with life-limiting illness. The terms 'palliative care' and 'end-of-life care' are often used interchangeably; this is confusing and makes the generation of evidence difficult. In this research, the term 'palliative care' is utilised in line with a palliative diagnosis, which is given when an individual is presented with a limited prognosis. Therefore, the disease can be terminal at diagnosis, for example, those with advanced prostate cancer, yet some individuals may be diagnosed but live with well-managed symptoms for many years, hence the intent is to treat as opposed to cure. The term 'end-of-life care' should be used in reference to the last days and hours of life.<sup>8</sup>

While the prominent success of ICPs at the end of life is clearly demonstrated in the literature,<sup>9–11</sup> evidence of the effectiveness of palliative care ICPs for those with life-limiting illness is lacking. The ICP draws on principles derived from many areas of healthcare including the LCP and chronic disease management. However, little is known about the transferability of evidence generated

in relation to the LCP and chronic disease management to a palliative care ICP; therefore, these factors are key parts of the study described here. There is also a lack of understanding about the detailed way in which the ICP may achieve success; information is needed on how positive outcomes are attained and for whom they are most beneficial. It would be premature to aim to establish linear cause and effect type relationships without first attaining a better understanding of the conditions for effectiveness. This ICP is complex, involving multiple organisations and a multidisciplinary style of work. It therefore requires a novel methodological approach to evaluation as described in this protocol.

Evaluation efforts for complex interventions are unlikely to establish firm linear causal relationships.<sup>12</sup> Taking a step away from seeking to find if a programme 'works' and moving towards highlighting the conditions necessary for success is crucial in complex intervention evaluation. The focus here is on the inner potential of a system: the interventions, the mechanisms, the changes in routine practice.<sup>13</sup> Pawson and Tilley,<sup>14</sup> the developers of realistic evaluation, present an explanatory formula which will be used throughout this study: outcome = mechanism + context. This formula purports that new initiatives' final results (outcomes) are dependent on the introduction of appropriate ideas and interventions (mechanisms) and the appropriate existing social and cultural condition (contexts). In metaphoric terms, causality is attributed to the right substance being activated in the right conditions. A simple time A versus time B comparison of data would not generate the understanding that is required. Therefore, this research aims to explore the inner potential of this palliative care ICP for individuals with life-limiting illness through context (C), mechanism (M) and outcome (O) conjectures and developing configurations. For example, in context A with mechanism B, outcome X is more probable. An example of this is provided in an attempt to modernise a health service<sup>15</sup>; in inner London (context), integrating services across providers (mechanisms) led to the patient having a seamless and consistent experience (outcome). The study described here is deemed complex according to the dimensions of complexity provided by the Medical Research Council,<sup>12</sup> which includes the number of groups or organisational levels targeted and number and variability of outcomes. In order to investigate the ICP, a three-phase protocol was formulated, which allows exploration of several realist evaluation conjectures. Each Context Mechanism Outcome (CMO) conjecture requires a different form of analysis thus requiring the development of a multifaceted analytical framework, as detailed in the remainder of the article.

### AIMS, OBJECTIVES AND RESEARCH QUESTIONS

#### Study aim

The study will aim to systematically investigate key features of contexts (GP practices, norms about palliative care, relationships among organisations), mechanisms

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(communication, staff training, IT systems) and outcomes (good death measure, reduced hospital admissions, practitioner, patient and family satisfaction) and their interactions in the ICP. It will identify and understand the features of a comprehensive palliative ICP for people with life-limiting illness.

### Research question 1

Does the palliative care ICP work? Are the factors that drive the palliative care ICP (Advanced Care Planning, Palliative Care Register, Do Not Attempt Resuscitation forms) all being utilised as intended? Does the ICP lead to a good death in both the GPs' and bereaved families' experience?

### Research question 2

What are the conditions of effectiveness of ICPs in palliative care, in terms of implementation context and intervention detail—for whom does the ICP work, how does it work and under what circumstances?

### Research question 3

Who does the ICP work for? What are the patients', families' and bereaved families' experiences and opinions of the ICP?

### Research question 4

Can patients' and health professionals' respective coping styles provide an explanatory framework for the research evidence indicating that conversations about palliative care are sometimes perceived as difficult?

### Objectives

- ▶ To describe and develop an understanding of the *contexts* surrounding ICP implementation and discover how these contexts influence outcomes.
- ▶ To describe and develop an understanding of the structure, organisation, interventions and general implementation of the ICP (*the mechanisms*) and therefore understand how the ICP works.
- ▶ To explore the perceptions of the ICP from those involved including patients (palliative), staff (primary and secondary care), carers and family and friends of patients (*mechanisms and outcomes*).
- ▶ To investigate conversations about palliative care between health professionals and patients, and the effect of coping style (*mechanisms and outcomes*).
- ▶ To identify, describe and assess a range of *outcomes* of the ICP.

### Design

#### Putting realistic evaluation into practice

There are three phases to the research, undertaken concurrently, within which the various CMO conjectures, generated as a starting point for exploration and understanding following immersion in the field and literature, are explored. It is believed that other CMO configurations are likely to emerge from the investigation, and this is embraced and accounted for by the research in terms

of its small participant numbers in all current sections of data collection. This allows the research to be flexible and responsive to emergent findings. This set up also inherently acknowledges the sensitive nature of the research and minimises research demands on participants. Within the three research phases, several analytical strategies will be utilised to make sense of the data (see section on Analytical framework). By highlighting the more beneficial contexts and mechanisms in different areas of the ICP, progress can be made in both refining and improving the ICP via feedback loops built into the design. Additionally, information about optimal conditions for implementation can be obtained, which will be useful for implementation of the palliative care ICP or any other similar health improvement initiatives, in other areas of the country.

### Analytical framework

The CMO conjectures referred to above will be investigated using analytical frameworks, referred to as phase maps (table 1). It is envisaged that outcomes from phase maps 1 and 3 will feed into phase map 2. This is in order to facilitate the initial focus group and to ensure that a good breadth of data from several sources is continuously fed back into subsequent focus groups. Table 1 details the type of participants in each section of research and explicitly indicates which data collection tools will be utilised, how data will be analysed and which research question is being addressed.

#### Phase 1: does the palliative care ICP work?

**MIQUEST and locality Death Audit data.** Data collection: Phase map 1 details the use of quantitative data available from the 15 pilot sites in the form of the Death Audit and Morbidity Information Query and Export Syntax data. Both sets of data are routinely collected by practices: Death Audit data retrospectively since 2007 and MIQUEST searches run routinely since 2009. While some of the data overlaps, other data, such as that on Advance Care plans and sudden deaths, do not.

Data analysis: Descriptive statistics will be generated from the MIQUEST and Death Audit data.

**The Quality of Dying and Death Questionnaire.** Data collection: There are several 'good death' measures available in the literature; however, a recent systematic review found the Quality of Dying and Death Questionnaire<sup>16</sup> to be the most widely studied and best validated.<sup>17</sup> It will be used to determine how many individuals who experienced the ICP had a good death. This measure will be distributed to bereaved families and key healthcare workers involved in a patient's care.

Data analysis: Descriptive comparison of perceptions.

#### Phase 2: what are the conditions of effectiveness of ICPs in palliative care?

Data collection: Focus groups with health professionals from many different backgrounds and services will be carried out. This will include the ambulance service, a hospice, GPs, community matrons, district nurses and



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**Table 1** Phase maps—study participants, data collection and analyses for each research question

	Major research question answered	Specific research question answered	Participants providing data	Data source	Data analysis
Phase map 1	Does the palliative care ICP work?	Are the palliative care ICP factors all being conducted appropriately?	Palliative care patients from one of the practice sites	MIQUEST data base/locality Death Audit	Descriptive statistics
		Does the ICP lead to a good death in both the GPs and bereaved families experience?	Relatives of deceased palliative care patients and the health professionals previously involved in the patients palliative care	Quality of Dying and Death Questionnaire	Descriptive comparisons
Phase map 2	What are the conditions of effectiveness of ICPs in palliative care?	In terms of implementation context and intervention detail—for whom does the ICP work, how does it work and under what circumstances?	Health professionals involved with the ICP	Focus groups	Soft systems methodology
Phase map 3	Who does the ICP work for?	What are the patients, families and bereaved families opinions and experiences of the ICP?	Palliative care patients and their families and bereaved families of palliative care patients	Interviews	Interpretive phenomenological analysis
			Palliative care patients and their GPs	Coping Style Questionnaire Voice recording of consultations	Classified as monitor or blunter Interpretive phenomenological analysis

GPs, general practitioners; ICP, integrated care pathway.

social services. Three focus groups will be conducted to allow an understanding of how the ICP works and therefore lead to a model that will represent the real-world ICP from practitioners' viewpoints. Furthermore, this model will help to highlight the contexts and mechanisms that are key to producing effective outcomes. It is envisaged that these focus groups may also enhance the ICP itself as they will provide practitioners with opportunities to reflect on the ICP and summarised discussions will be fed back. This will allow the research project to build on practitioners' combined organisational memory, experience and wisdom.

**Data analysis:** Soft systems methodology (SSM) will be the analytical framework for this section of research. It is an epistemology that formulates carefully built models of systems, which will be used to represent and analyse the real-world situation. They will then be set against perceptions of the real world by a process of comparison, which will initiate debate leading to solutions of how to improve the real-world situation through purposeful action.<sup>18</sup> SSM aims to provide assistance in coherently expressing and operating the learning cycle from meanings to intentions to relevant action without the rigidity of a technique.<sup>18–19</sup> SSM has been used to aid understanding in public health, outpatient services and chronic

disease management<sup>20–22</sup>; however, it has not yet been used in the investigation of a palliative care ICP. The use of focus groups will aid in the validation and development of the SSM map and also help the ICP grow and mature into a more efficient and effective initiative, as in Tolson *et al.*<sup>23</sup>

### Phase 3: who does the ICP work for?

**Coping style.** Data collection: A palliative diagnosis or information about palliative care can both be classed as distressing health-threatening information, which is difficult for the doctor to deliver and for the patient to receive.<sup>24–26</sup> The literature suggests conversations about death occur infrequently and that this may be due to professionals not feeling at ease with broaching the subject.<sup>27–29</sup> It is proposed that in such health-related risk situations, individuals utilise distinctive attentional processing styles, which allow them to be classified as a high or low monitor.<sup>30</sup> When faced with a health-related risk, high monitors generally seek information, magnify disease-related cues and display greater dissatisfaction about the amount of information provided. Alternatively, blunders psychologically distract themselves from health-related risk information and desire less knowledge.

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The proposed use of coping style classification in this project will be to investigate whether matched coping styles between patients and health professionals offer any explanatory potential for outcomes achieved. For example, if a monitor health professional and a monitor patient (classified through use of the Miller Behavioural Style Scale)<sup>30</sup> have a consultation, it is hypothesised that their conversation about death will have a more positive outcome than a conversation between a monitor health professional and blunter patient. Individuals will be classified as monitors or blunterners, and following from this, recordings of conversations/consultations about palliative care will be made.

**Data analysis:** The questionnaire data will be analysed by classifying individuals as monitors or blunterners. The audio recording of the consultation will be analysed using thematic analysis. It is acknowledged that palliative care conversations take place over time. Therefore, GPs will have the opportunity to record up to three consultations with one patient, if they believe that this is necessary.

### *Interviews with palliative patients and bereaved family members.*

**Data collection:** Semi-structured interviews will be conducted with palliative care patients, their families and friends, and bereaved families and friends of palliative care patients. This provides rich in-depth qualitative data about the ICP, whether it is working for patients and family of patients and if it contributes to a good death. It is also envisaged that information from these interviews will feed back (anonymously) into the focus groups with the healthcare professionals in order to facilitate SSM modelling.

**Data analysis:** The transcripts of the interviews will be analysed using IPA.<sup>31</sup>

### Participants

In order to fulfil the research aims, the study will recruit GPs, nurses, charity staff from local organisations, the ambulance service, community matrons, social service staff, palliative care patients, bereaved family members, and friends and carers of palliative care patients.

In each different CMO conjecture, a different practice will be selected for data collection, from the 15 practice sites. This will avoid over burdening health professionals, palliative care participants and bereaved family, friends and carers of palliative care patients. The three practices selected are rural, semirural and urban. Palliative care participants will be selected via a GP screening method to ensure no one is contacted who is suffering from cognitive deficits or severe psychological distress. Palliative care patients and bereaved family members, friends and carers will be invited to participate in the study via letter. Health professionals will be invited via email or letter.

### ETHICS AND DISSEMINATION

Research suggests that ICPs in end-of-life care are successful,<sup>5–7</sup> and therefore, a similar approach to the

palliative care of those with life-limiting illness may be beneficial to staff, patients and families. However, examination of syntheses of this research indicates that currently the literature in this area is sparse. This study is part of a PhD thesis that aims to elucidate if the new ICP works and, if so, how it works and who it works for. Several outcomes are anticipated from the study, including: trends in quantitative measures from MIQUEST data and locality Death Audit data, qualitative information from the interviews, focus groups and Quality of Dying and Death Questionnaire, SSM models of the ICP and innovative information on coping style and communication in palliative care. These outcomes will allow the generation of knowledge about the key operational factors that make the ICP a success and how these are influenced by delivery context. Additionally, this study will generate knowledge about the ICP that will improve it via feedback while the research takes place and will provide information to aid implementation of the ICP in other geographical areas.

The study will also highlight gaps in knowledge about palliative care and therefore the development of novel forms of care may be created and implemented as a result. This new knowledge could be utilised by a wide spectrum of organisations and individuals working in this area including new clinical commissioning consortia, GP practices, acute hospital trusts, specialist palliative care services, social care, community services, registered charities, educationalists, patient advocates, and policy makers to guide ICP implementation, service delivery and service improvement. Currently, there is a vast amount of policy and little practical implementation<sup>12</sup>; this study may aid in implementing a long-term change in the GP practice sites.

The ICP has been implemented since January 2010 in one locality of Northumberland involving 15 GP practices serving 80 300 patients. A 1-year data collection phase commenced in March 2012. The use of qualitative and quantitative data means that there will be a considerable amount of data generated with a wide range of outcomes. The quantitative MIQUEST and Death Audit data from the 15 GP practices involved with the ICP, and study dates back from 2009 to 2007, respectively, and includes many outcomes; therefore, it yields a considerable amount of information about various outcomes over a substantial period of time.

### Ethics

The conduct of the study will conform to relevant ethical and legal guidelines covering informed consent, confidentiality and data storage. Ethical approval was obtained from the LREC through use of the Integrated Research Application System on 12 January 2012. Research and Development approval was gained from four different NHS trusts due to the various participant groups in this study. The voluntary sector and the council were also informed of the study, and permission has been gained to invite their staff to participate in the study where appropriate.

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### Dissemination

This study is large scale and will form a PhD thesis and will be available in hard copy in Northumbria University library and via the university's online repository once completed. As data collection occurs, platform presentations will be given and academic posters will be displayed at relevant conferences. Additionally, publications will be drafted; therefore, each section of data collection has a potential for publication. Potential publications include mapping of focus group's discussions surrounding the palliative care ICP; analysis of bereaved family members' experience of terminal care and caring for a loved one; an IPA of patient's experience of palliative care; a statistical review of MIQUEST and Death Audit data; results from a matched health professional and bereaved relative Quality of Death and Dying Questionnaire; coping style and palliative care relationships and their effect on consultations. All data that are collected will be utilised in the realist evaluation, and publications are also expected from this analysis. The results from the study will also be fed back to the locality as they are analysed in order to aid continuous quality improvement.

### Steering group

This research has a dedicated steering group, which aims to monitor progress of the study, address governance and ethical issues and overcome barriers in access and resources. The steering group includes experienced researchers from Northumbria University, a GP with expertise in palliative care, a service user, a palliative care Masters programme leader from Northumbria University and a Research & Development lead representing the NHS study sponsor. This steering group has been important in both setting up the project and achieving milestones such as LREC and Research & Development approval.

### Conclusions

A novel and complex approach to practice has been matched with a novel and complex evaluation methodology. While much of the learning generated by this research will be on palliative care processes, there will also be key methodological messages about developing CMO conjectures early in a project and populating them with evidence.

**Contributors** SMD created the design of the study with supervision and guidance from DJ, ML and BC. SMD produced the draft manuscript, and DJ, ML and BC have revised the manuscript critically for important intellectual content. All authors read and approved the final manuscript.

**Funding** SMD is jointly funded by the Northumbria University and NHS North of Tyne Primary Care Trust. DJ and ML are funded by Northumbria University. BC is a retired general practitioner.

**Competing interests** None.

**Patient consent** All participants in this study will remain anonymous. Their names will not be used and there will be no pictures of them available. A consent form has been signed for participants to agree to take part in the study but only anonymously.

**Ethics approval** Ethics approval was provided by the Newcastle and North Tyneside 1 Research Ethics Committee. REC reference number: 11/NE/0318.

**Provenance and peer review** Not commissioned; internally peer reviewed.

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